Starting a hospice - is it a good thing or is there any risk?

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Att hospice allmänt anses vara något bra bevisas bäst genom dess stora spridning världen över. Under de sista tre decennierna har hospice etablerats i ett 60-tal länder.

Hospicevård förutsätter inte speciella lokaler utan essensen innebär att man utarbetar och tillämpar en speciell filosofi. Denna kan sammanfattas i att döendet ses som en normal process och att den sista fasen i en människas liv är en tid av eftertanke och försoning. Den döende människan tillerkänns ett behov av att leva i värdighet och välbefinnande livet ut. Detta förutsätter att personalen tillämpar ett speciellt förhållningssätt liksom att de har speciella kunskaper. Målet ”att maximera den döendes livspotential” kräver också kontroll av patientens fysiska, sociala, känslomässiga och andliga symtom. Detta i sin tur fordrar ett flerdisciplinärt, samarbetande personalteam liksom stöd till patientens närstående. Planeringen av hospice måste börja med att fastställa de faktiska lokala behoven av hospicevård. Allt för små enheter riskerar att ge sämre kvalitet. Att utveckla goda relationer till andra vårdgivare är viktigt eftersom det finns risk att hospice uppfattas som en konkurrent och som kritik av andra vårdalternativ. Hospice har en väsentlig roll när det gäller utbildning och klinisk forskning.

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Introduction

That hospices are widely thought to be a ”good thing” is best evidenced by their extensive duplication around the world, now occurring in nearly 60 countries, and in particular, by their spread in Britain, the country in which they originated. Here, from a handful in the 1960’s and still only 25 in 1973, there are now 178 hospices in operation.

But the question arises - what is meant by a hospice?

In Britain forms of palliative care provison other than in-patient hospice units have shown a yet faster rate of growth. From the first Home Care Team, founded at St. Christopher’s in 1969, there grew 40 teams by 1980 and 360 by this year. Fifteen years after the first British Hospital Support Team there are now 160 teams. Most rapid of all, 1 day hospice in 1980 had become 186 day hospices by this year. These increases have been largely initiated by charitable money, and except for many of the home care services, continue to be funded for the most part by public donation, with no charge being levied on patients and only a lesser share of finance originating from the Government. British people have backed hospice care with their own money.

Hospice philosophy

It appears, therefore, that in Britain, at least, there is widespread public agreement that hospice services are ”a good thing”. But hospice services do not necessarily mean bricks and mortar, although an in-patient unit is the ambition and, indeed, achievement of many fundraising groups. Rather, hospice is essentially the working out of a philosophy. This philosophy has been summed up as follows:

> ”Hospice care recognizes that dying is a normal process, and that for the dying person the last phase of their life is a special time for integration and reconciliation. It regognizes the need for dying people to live fully with dignity and comfort until they die, and neither precipitates nor postpones death. Finally, it provides ongoing support for bereaved families and friends.”

Implicit in this philosophy is the recognition of each

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dying person as an individual, in regard both to his personality and to the particular symptoms that he has. A result of individuality is individual preference, including preference for style and place of care. It is because the majority of people appear to want to die in their own homes that there has been such a growth in domiciliary hospice services. It is because a large number of people, even those with cancer, die in general hospitals that teams are being formed to facilitate the hospice style of care in a hospital setting. In Örebro you are setting up an in-patient hospice; some of you here have already done this and others would like to do so. There *is* a need for in-patient hospice care - despite all the support that can be offered at home, for some people the stage will come where suffering and distress for them and their families can be minimized only through admission to a specialist unit. But it is important to see that hospice care is not dependent on buildings but on the skills and attitudes of staff.

Skills and attitudes of staff

What are the essentials of those skills and attitudes? Perhaps the most fundamental is that people whose disease is incurable are not regarded as failures and their care as the limited and unrewarding practice of those lacking the ability to work with curative therapies. Quite the revers - the rewards may be different but the principles of care of terminally ill people are in many ways the same as those of the best care of ill people of any description.

Symtom control

The fundamental skill in hospice care must be symtom control, because without relief of pain and other physical and emotional distress little else can be achieved. Remember that although hospice care is about dying it is even more about living until death occurs, with the implication that each person is encouraged to find and work out their own aims to their fullest ability. This cannot happen without the control of symptoms.

Symptom control requires knowledge in the use of drugs and other measures. It also requires that the person is recognized as more than a physical entity and their symptoms as more than determined simply by physical factors, but also by the social, the emotional and the spiritual.

Interdisciplinary team

No one person can do all this. Symptom control requires a team: there may be several teams involved in the care - a medical team, a nursing team, maybe a social work team and a chaplaincy team - but to provide effective hospice care these separate teams must come together as appropriate for the individual patients as an interdisciplinary team. Interdisciplinary working is a key feature of hospice care and recurs again and again in any discussion of this subject.

Family support

The interdisciplinary hospice team will have the concern not only to control a person's symptoms but to help that person to reap the benefits of their comfort as fully as they are able, in other words to maximize their potential for life. For most people the realisation of their potential is intimately dependent on personal relationships, usually most importantly those with their family. It is imediately apparent that hospice care properly expressed cannot be care of patients as isolated individuals but must include the family as an intrinsic part of its concern. The aims that have to be worked towards in this last phase of a person's life can be decided only by the patients themselves, but family support for the process is important and, indeed, often the aim is that of family reconciliation. At St. Christopher's, the median duration of stay in the hospice has fallen steadily over the years and is now only obout 10 days. Nevertheless, it is astonishing how much can be accomplished in a brief time under the stimulus of the crisis of approaching death. Longstanding problems are not infrequently resolved in days or even a matter of hours.

Again, interdisciplinary teamwork is needed to help patients and families passing through these rapid transitions, and communication must be a main emphasis, not only between the team and their clients but between team members themselves. Much work in hospice services is directed towards facilitating

Hospice care must include the family as an intrinsic part of its concern communication within families and although if the service has a social worker they are likely to take the lead here, just as the doctor will take the lead in symptom control, communication must be a concern of all staff members.

Families are not, however, simply the recipients of our care. At home they are the patient's chief carer and they must not feel marginalised if admission to a hospice occurs. In many practical ways, from mouth care to helping the person to a more realistic view of their illness, they can become part of the hospice team itself.

Bereavement support

A service that cares not only for patients but also for their families cannot simply withdraw when the patient dies. Most relatives will cope with bereavement without professional support, but for a minority - in our experience around 25% - such support can greatly help their adjustment to loss and may improve their long-term health. In all this, for both patients and families, the spiritual must not be overlooked. This does not necessarily mean the religious, but rather the questions about the meaning of the experience of incurable illness, debility and loss which come to very many people who undergo it. These questions lead to consideration of the most fundamental meanings of all - of the life that is drawing to an end and of oneself as an individual in the world, and face not only those in our care but also ourselves, as professionals whose patients are not cured, who see death frequently and who regularly endure what to many medical personnel is defeat. In order to meet these questions an interdisciplinary team is, once again, required, providing the range of professional skills and individual personalities needed and also support of members for each other. Each member must, nevertheless, have their own philosophy for coping with loss and their own ways of finding support when the burden seems very heavy.

Risks in starting a hospice

Assesement of local needs

If a hospice is a good thing, and these are its elements, is there any risk in starting one? Yes, of course there is. The most fundamental risk, perhaps, is that of founding a service which is inappropriate to local needs. St. Christopher's may have been the first modern hospice but it is not a blueprint för British hospices in general and certainly not for Swedish ones. There must first of all be assessment of the local needs - what patient group is to be served (it need not be exclusively cancer: many British hospices take MND and AIDS, some other diseases as well); how many of them are there; over what area do they live; what other facilities are available or planned and where? Constructing a building implies considerable expense and hence probably extra delay while the money is found. A single in-patient unit may be of little use in serving a sparse, widely-scattered population. In these situations a home care team, or possibly a day hospice, might be a available more quickly and either be more appropriate to local circumstances or be an interim measure until a hospice building can be built. In Britain, a provision of about 50 hospice beds per million of population has been thought adequate.

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Co-operation and co-ordination with other health services

It has been said that starting a hospice is something that should not be done unless you really cannot help it. This is because it is very hard work, requiring real commitment and leadership, pimarily from a single person. The enthusiasm of such a person must be tempered by reality. Most British hospices are independent of the National Health Service and the resultant control over their own policy has been of enormous value in the development of the speciality. But independence can be carried too far. Hospice patients will come from the government health services and will often continue to receive treatment from those services while also under the care of the hospice. Increasingly, general hospital and community services are making provision for the care of terminally ill patients. It may be that the hospice could help them in doing so by offering to help with joint clinics. For all these reasons, co-ordination with regional health planning is most important, to avoid duplication and misunderstandings and to ensure correct assessment of present and future needs. In addition, financial help is unlikely to be forthcoming from central sources unless such co-ordination has been achieved.

A hospice must be medically respectable and, among other factors this means being large enough to give the best quality of medical, nursing, paramedical and administrative practice. Hospices are small, by comparison with hospitals, but they should not be so small that their availabililty of services and expertise is inadequate. A very small hospice is not necessarily better than no hospice at all, and the community might be better served by the amalgamation of neighbouring hospice projects so that a larger unit can be built with their pooled resources, or by domiciliary service with designated beds in local hospitals or nursing homes. A small unit is also inefficient to run - in Britan the lowest cost per bed is achieved with units of about 25 beds.

The success of any hospice ultimately depends on good relationships with other health professionals. Discussion with local doctors and community nursing services should begin at an early stage. This is even more vital if a domiciliary service is envisaged. Other health professionals may feel that the hospice will infringe an area of patient care that is rightfully theirs, they may feel that - if only by implication - their care is under criticism, they may fear competition for health funds. Any of these perceptions produces a sense of threat which if not dealt with by explanation and the maintenance of good channels of communication, will limit the hospice's effectiveness. Eventually, of course, the most effective way of breaking down barriers is for the hospice to prove its clinical worth and establish a good reputation which spreads through the community it serves, both lay and professional.

Identification with the local community

If the hospice is to be reliant on charitable funds its identification with the local community must be strong if funds are to continue to be raised. The service must be seen as highly relevant to their needs and a source of local pride. There should be ample opportunities for people to learn of its work and to be involved in the support of the hospice.

Such local community involvement will also assist in a more accurate image of the hospice being held by prospective patients. Hospice only too easily become thought of as "death houses". This risk should be minimized by a policy of admitting not only those who are likely to die very soon, but also patients who, if symptom control is achieved, will return to their homes, and patients whose families need a short respite from caring for them. In these ways the fears that admission to the hospice will be a "one way ticket" will be reduced. The establishment of a home care service as an outreach from the hospice is an immense advantage in facilitating transfer of patients to and fro between hospice and home and the team can also act as ambassadors for the hospice's work. 137 of the 360 Brittsh home care teams are attached to hospice in-patients units and many of the others work in close liaison with a hospice. If possible a home care service should be planned from the start and, as I have said, may precede the opening of an in-patient unit. If the latter is the case, careful thought should be given to the medical support available to the nurses who will work in the team, as there is otherwise the risk that they will suffer through feeling isolated and have difficulty in establishing their credibility with existing services.

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Learn from others

As you are doing through this conference, it is important in starting a hospice to look at what others have done and learn from it - but not be bound by it. Hospice care is characterised by a diversity of responses, shaped by local need. In preparing for an in-patient unit the architect should be selected early and, if possible, should have experience in this field. He should be invited to the preliminary discussions where he should be able to help shape your plans. You should be ensuring that the building is appropriate in cost and design, by attention to such features as: a high proportion of single rooms in the accommodation, open bays of appropriate size (4 people in a bay seems, from experience, to be best number), provision for relatives to stay overnight, accessibility of all patient areas to both wheelchairs and beds, and provision of a mortuary of adequate size with direct access.

The hospice staff

Selection of staff for the hospice is a vital process. Senior medical and nursing staff should preferably be in post before the final fitting-out of the unit so that they have an opportunity to make the type and layout of equipment appropriate to the way they see the organisation functioning. They should also, if possible, have training and experience in hospice work either within the country or abroad. If they do not, it should be a condition of employment that they gain such training as early as possible after their appointment.

Many terminally-ill patients are highly dependent and this should be reflected in the nursing ratio, which will be in the region of 1.1 or 1.25:1 overall. There is otherwise the risk of further impoverishment of nursing ratios through physical injury, and an empahsis on physical care to the exclusion of conversation and counselling because of lack of time. The nursing team needs to have a high degree of technical competence if good standards of symptom control are to be achieved and hence as large a proportion as possible of the complement must be trained and any auxilliary nurses, if they are employed, should be educated appropriately by the hospice.

A hospice requires continuous medical cover, but a further problem of small units is their inability to support more than one or two doctors. To these people it falls to provide all out of hours cover. This is either a considerable strain upon them or results in an often haphazard of covering doctors chosen from those who are willing to work voluntarily or for very little rather than necessarily from those who are knowledgeable and competent in the field. As well as militating against good patient care this makes life very difficult for the nursing staff. There should be advance planning for medical staffing.

People apply for jobs in hospices for all sorts of reasons and the aphorism that you should be prepared to employ the unlikely but not the unstable is to be taken seriously. It is also wise to avoid those who see hospice as an opportunity to work out their own bereavements or guilts. Those who have experienced loss in their own lives may have much to offer patients and families, but not until they have had time properly to integrate that experience.

Contrary to what is often supposed by those not in hospice, the work is not on the whole found unduly stressful by most people who do it. Nevertheless, it does have times of great sadness, pain and anger and if the quality of care is to be maintained and staff wastage minimized, thought needs to be given to support for staff members - and that means *all* staff members. How such support is provided depends on the culture, both national and that of the institution. It does not necessarily involve special "support groups": it certainly will involve the readiness of staff members as individuals and as a team to be aware of colleagues' workloads, sensitive to signs of stress in others and willing to offer tactful acknowledgement, listening and practical action across disciplinary boundaries.

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The hospice in the future

I spoke earlier of the importance to the success of the hospice service of avoiding a sense of threat to fellow professionals. In part this is done by prior consultation and by continuing communication. It is also done by having an appropriate view of the hospice's role. Hospices are not founded to take over a segment of existing health care provison. Approximately 1 in 4 people die of cancer - that is a lot of people dying each year of this type of disease alone. Hospices are not big enough to take over this care entirely, but have to be complementary to other facilities, demonstrating an exellence in care of the terminally ill and enabling this care to be carried out better in all the other places in which it is performed. Hence the various forms in which hospice services are found, hence the need for hospice services to fit in with regional health plans and not to be functioning in isolation. Hence also my final point - that from the hospice's inception an educational role must be envisaged and planned for. There is circumstantial evidence in Britain that the presence of a hospice improves symptom control in local hospitals. This happens both by formal teaching and by informal, by the fact that there is now someone to phone up and ask about the problems posed by a terminally ill patient. It is likely to happen all the more effectively if it is known that the hospice is actively auditing its practice and pursuing a programme of clinical research. Unless these things are there from the beginning, there is the risk that the hospice will not be taken seriously by members of other medical specialties and, more significantly, that it will not deserve to be. Hospice work is not as hard as some make it out to be, but it is not easy either. No unit can avoid all the pitfalls, but I have tried to point out some ways in which the pits may at least be made rather shallower. I whish the hospice in Örebro very well indeed.